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### Sexuality and amputation: a systematic literature review

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## REVIEW

# Sexuality and amputation: a systematic literature review

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### Abstract

**Purpose.** To systematically examine the state of research on sexuality and amputees.

**Methods.** A total of five publication databases were searched: Pubmed, Cinahl, Embase, Psycinfo and Recall.

**Results.** A total of 11 eligible studies was found. The studies were characterised by a diversity of study populations, sampling methods, gender and age distributions, assessment methods, and outcomes measures. The use of the terminology regarding sexuality was ambiguous. All studies found an impact of the amputation of a limb on some part of sexual functioning (or concerns about) to some degree.

**Conclusions.** Studies on sexuality and amputees are very diverse and terminology is ambiguous. Amputation of a limb has an impact on sexual functioning. Amputees complain that there is little support from professionals. The authors recommend the use of the ICF terminology. Suggestions for future research are given.

**Keywords:** Sexuality, systematic review, amputation

### Introduction

In the Netherlands, annually 3000 major amputations of a limb are performed (1.9 per 10.000). In other countries, the numbers of first major amputations range from 1.2 to 4.4 per 10.000 [1]. These rates of all-cause acquired amputations are from women in Japan and men in the Navajo population respectively [2]. The majority of amputations are performed on the lower limb. In the Netherlands 86% of the amputations are performed on the lower limb [3].

Worldwide the risk of amputation is the greatest in persons with diabetes mellitus [1].

Reasons to amputate a limb are vascular, trauma, oncology or life threatening inflammation. The major part (76%) of the amputees is older than 65 years because most amputations are performed due to vascular reasons [3].

After the amputation patients try to continue their lives as before. However, an amputation induces

several limitations in performing professional, leisure, social and marital activities including sexual activities.

In literature concerning amputation, limitations in sexual activities of amputees are discussed. In these papers it is assumed that problems in performing sexual activities are hindered in different ways, related to the type and level of amputation and the cause of the amputation [4,5]. Depending on the type and level of amputation patients may have difficulties in obtaining their desired position. 'Lying on top' resting on a partner may be impossible after a transfemoral or transhumeral amputation. Moving from one position to another position during sexual activities is hindered by loss of (part of) a limb. Also stability of the position during intercourse may be difficult when a limb is missing [4].

Missing a hand or a larger part of an arm may influence the possibilities of stroking and caressing (stimulating) their partner. Additionally masturbation may be hindered.

Pain in the stump or phantom pain is frequently present after amputation of a limb [6]. These types of pain may hinder or prevent libido. This hindering of libido may also prevent or reduce sexual activities. In male patients these vascular problems are frequently associated with erectile dysfunctions whereas in female amputees vascular problems are associated with lubrication dysfunction [7]. Amputations performed for oncological reasons may be associated with a reduction in erectile functions in males due to chemotherapy and less lubrication in females. Because most amputees are older than 65 years cardiac dysfunction may interfere with their sexual activities.

Apart from the above mentioned problems amputees may have a negative self image due to the amputation [8]. The reduced mobility of the amputees may make it difficult for them to come into contact with possible sexual partners who in turn may reject the amputee as a possible partner. However, little scientific data are available to substantiate the above-mentioned assumptions.

The aim of this systematic review is to provide an overview of the knowledge of the field of sexuality and patients who have suffered from an amputation of an arm or a leg.

## Methods

In Medline, Cinahl, Embase, Psychinfo and Recall (all until June 2006) publications were searched with 'amputation(s)' as the free text word (or amputee(s), congenital amputation(s), congenital amputee(s)) 'and' 'sexology' (or sexuality, intimacy, intimate, sexual, (psychological) sexual dysfunction, sexual coping, sexual rehabilitation, sexual rehabilitation, sexual behaviour). Papers were included in this review if they described research in which the sexual (dys)functioning of a cohort of extremity amputees was investigated. Excluded were reviews, expert opinions, case-studies ( $n < 10$ ) as well as papers not dealing with limb-amputees. In this systematic review case studies ( $n = 12$ ) were excluded because of the anecdotal evidence. The papers identified were checked for relevant papers in the reference lists. The papers were read and the following items were assessed:

- author
- year of publication
- description of population
- extremity amputation
- number of participants
- age of amputee
- reason for amputation of the population studied
- post-amputation period
- study design (cross-sectional or prospective)

- sampling method
- method of assessment (interview or questionnaire)
- outcome measures
- main results

The results of this assessment were entered in a database.

## Results

In total, 158 publications were found in Pubmed, 108 in Cinahl, 98 in Embase, 41 in Psychinfo and 13 in Recall were identified. After subtracting publications indexed in more than one data base, a total of 335 publications remained. After reading abstracts and excluding publications concerning other amputations than a lower and/or an upper extremity for instance penis or breast, and deleting reviews, expert opinions and case-studies ( $n < 10$ ), a total of 19 papers were left for reading of the total manuscript. Of these publications only 11 studies fulfilled all inclusion criteria for this review [8–18]. Eight papers were rejected because sexuality appeared not to be the focus of research; only existing literature was repeated or amputees were not identified separately in the cohort population.

In Tables I and II a summary of the different studies is presented.

The studies are characterised by a diversity of study populations, sampling methods, gender and age distributions, and assessment methods and outcomes measures. The studies were published between 1945 and 2002. Populations came from different countries: the USA, Japan, Nigeria and Denmark. Patient samples included upper limb amputees or lower limb amputees or a mixture of both. Amputations were performed for war related injuries, vascular diseases, trauma, infections, and cancer. In some studies a small sample of patients with congenital limb defects was included. The mean age ranged from 26 years to 57 years. The maximum age was 84 years. Studies samples were drawn randomly or were convenience samples. Some samples included only males and in other samples males and females were included. All studies were of a cross-sectional design. The assessment methods were interview or questionnaire. In some studies a part of the study population was interviewed and another part filled out a questionnaire. The time interval between amputation and research ranged from 6 months to at least 20 years.

All studies found an impact of the amputation of a limb on sexual functioning (or concerns about) to some degree [8–18]. Many different outcome measures were assessed in the studies such as sexual adjustment, frequency of intercourse, sexual functioning, position of intercourse, sexual arousal,

Table I. Overview of studies investigating amputation and sexuality: a description of sampling, study population and study design.

Author	Year of publication	Social context population	Reason for amputation	Sampling	Participants (m/f)	Mean age (SD)	Design	Extremity (n)	Method	Post-amputation period
Randall	1946	Soldiers in the 'orthopaedic section' USA	76% Battle casualties, 24% non battle casualties	Random sample of 'normal patients'	100/-	26.4 (5.0)	CS	UL (32), LL (68)	Interview, Rorschach test	Not specified
Kegel	1978	Patients from hospitals in the Seattle area, USA	48% Vascular, 35% trauma, 8% oncology, 7% congenital	134 of 350 amputees treated between 1964 and 1976, 3 months after rehabilitation	103/31	45.0	CS	LL	Questionnaire	6 Months to 12 years
Reinstein	1978	Patients seen in an amputee clinic, USA	48% Diabetes, 23% vascular, 22% trauma, 7% oncology	60 Selected of 100	39/21	Not specified	CS	LL	Interview	<3 years
Akesode	1981	Patients from orthopaedic hospital and army rehabilitation centre, Nigeria	37% Road traffic accident, 33% war injuries, 13% ulcers, 9% occupational related, 7% others	Convenience sample	81/19	29.7	CS	UL(10), LL (90)	Questionnaire	Not specified
Medhat	1990	Patients from Veterans hospital and University Medical Centre, USA	Diabetes, vascular, trauma, gangrene, infection	327 Questionnaires sent, 131 returned	122/9	58.0	CS	LL	Questionnaire (PPIS)	Not specified
Kellaa	1992	Patients from Funen, Denmark	6% Vascular, 65% trauma, 5% oncology, 15% congenital, 9% brachial plexus lesion	Amputation between 1900 and 1987	52/14	45.1	CS	UL	Questionnaire	Mean 20.6 years
Williamson*	1996	Patients from outpatient clinic and amputee supporting organisations, USA	42% Vascular, 34% trauma, 7% oncology, 12% limb deficiency	Convenience sample at least 1 month post-amputation	51/25	Range, 29-84	CS	UL (21), LL (55)	Interview (67%), survey (33%)	Mean 14.6 years
Walters*	1998	Patients from outpatient clinic and amputee supporting organisations, USA	42% Vascular, 40% trauma, 6% oncology, 12% limb deficiency	Convenience sample at least 1 month post-amputation	51/26	57 Range, 29-84	CS	UL (21), LL (56)	Interview (67%), survey (33%)	Mean 14.5 years
Bodenheimer	2000	Patients from regional amputee clinic, USA	-	Sampling during 6 months	30/-	57.0	CS	LL	Interview/questionnaire, (DISF)	Median 23 months
Ide	2002	Patients from a rehabilitation centre, Japan	88% Trauma, 12% disease	Selection out of 306: 127 met inclusion criteria, 85 participated	71/14	46.8 (11.5)	CS	UL (25), LL (64)	Questionnaire	Mean 12.2 years, SD 9.7
Refaat	2002	Patients with sarcoma of lower limb, USA	100% Oncology	Amputees selected out of total of 342 patients treated for sarcoma	41/25	52.0 (20)	CS	LL	Questionnaire <sup>†</sup>	12 Years

m/f, number of males/females; UL, upper limb; LL, lower limb; DISF, Derogatis Inventory of Sexual Functioning; PPIS, Prosthetic Problem Inventory Scale; CS, cross-sectional.

\*Probably the same study sample although reasons for amputations is different.

<sup>†</sup>74% Missing data on erectile and potency problems.

Table II. Main results of studies investigating amputation and sexuality.

Author	Year of publication	Outcome measures	Results
Randall	1946	Sexual conflict and concern about sexual function	Rorschach test: indicated that 81% of amputees experienced sexual conflicts; in the interview, 30% of amputees admitted great concerns about sexual functions; married soldiers have less concerns about sexual function than single soldiers
Kegel	1978	Sexual functioning	15% of the amputees (8% of TT, 22% of TF and 33% of bilateral amputees) reported that their sexual function/life was affected
Reinstein	1978	Frequency of sexual intercourse	77% of male amputees and 38% of female amputees reported a decrease in frequency of intercourse; decrease in frequency was attributed to impaired sexual functioning (arousal, erection, ejaculation/orgasm), decreased mobility, decreased interest and fear of injury; decrease in frequency was larger in non-married men compared with married men, for TF amputees compared with TT amputees and for male amputees who still experienced phantom pain compared with those who no longer experienced phantom pain; 15% of the amputees discussed sexual activity with a health professional
Akesode	1981	Sexual problems	8% of the amputees reported a decreased urge for sex and 20% of the amputees experienced an increased discomfort after the amputation
Medhat	1990	Climax, position, satisfaction, response, partner response, libido	13% of males experienced change in libido
Kejlaa	1992	First sexual experience	TF amputees tended to experience more problems (but not significant) than TT on the items sexual desire; sexual potency, sexual positioning, frequency of intercourse, degree of satisfaction, sexual climax, partner response and sexual response; sexual activity was not a serious problem
Williamson*	1996	Sexual activities before and after amputation; actual sexual activities, satisfaction with frequency and quality of sexual activities	Sexual debut of upper limb amputees who had their first sexual experience after the amputation was averagely 3 years later compared with upper limb amputees who had their debut before amputation
Walters*	1998	Quality of life	76% of the amputees felt restricted in their sexual activity due to the amputation; 9% of the amputees received advice about sexual activity; being older was related to less sexual activity; impact of amputation on sexual activity was larger for single amputees compared with married amputees; impact of amputation on sexual activity was larger for older amputees compared with younger amputees; impact of amputation on sexual activity was larger when the time elapsed since the amputation was less; impact of amputation on sexual activity was for larger those amputees who experience amputation related pain compared with those who did not experience this type of pain; impact of amputation on sexual activity was larger for those amputees who felt uncomfortable in intimate situations compared with those who felt not uncomfortable; impact of the amputation was larger for those amputees who experienced that their spouse was bothered looking at the stump or prosthesis
Bodenheimer	2000	Sexual function, fantasy, arousal, sexual behaviour experience, orgasm, sexual drive and relationship, coital position, sexual functioning & prosthesis and pain & age & sexual functioning	Sexual satisfaction and amputation related pain were related to overall quality of life
Ide	2002	Talking about sex, sexual activities and satisfaction	Majority of amputees experience some problems with sexual functioning; 77% of the amputees scored 1 SD lower than normalised scores on the DISF; 67% of the amputees experienced arousal problems; 90% of the amputees remains interested in sex; amputee 'supine' was the position most frequently used (70%); a striking contrast exists between desired frequency of intercourse and actual sexual activity; amputees over 65 years experienced more sexual problems than younger amputees
Refaat	2002	Impotence and an active sex life	44% of the amputees talked about sexual issues with some one in daily life non-talked with medical professional; 60% of the amputees engaged in intercourse; 42% of the amputees reported changes in sexual life; 45% of the amputees was dissatisfied with sexual life; 31% of the amputees experienced a decrease in sexual interest
			26% of the amputees were impotent; 88% of the amputees maintained an active sex life

TT, transtibial; TF, transfemoral; DISF, Derogatis Inventory of Sexual Functioning.

\*Probably the same study sample although reasons for amputations is different.

erection, impotence, orgasm, communication about sexual activity/problems, mobility during sexual activity, pain experienced during sexual activity, fear

for injury, sexual satisfaction, desired frequency of sexual activity, and first sexual experience (Table II) [8–17].

The magnitude of the impact of the amputation differed for subgroups of amputees. Single amputees experienced more impact of the amputation on (concerns about) sexual functioning compared to married amputees [8,15,17]. Elder amputees experienced a larger impact of the amputation on sexual functioning compared to younger amputees [8,10]. Transfemoral amputees experienced more impact of their amputation on sexual functioning compared to transtibial amputees [13,14,17]. Amputees who suffered from amputation related pain such as stump pain or phantom pain or discomfort from the prosthesis experienced a larger impact on their sexual function compared with those who did not experience these sensations [8,9,17]. For male amputees the impact on sexual functioning was larger than for female amputees [9,17].

Some contradicting findings were found. In some studies sexual functioning after an amputation was not a serious problem [10] or only a minority of amputees reported problems [9,13]. In other studies a substantial amount of amputees reported some kind of problem in sexual functioning [8,10,11,17]. In one study the influence of sexual activity of amputees was analysed in relationship to depression and quality of life [8,18]. Satisfaction with one's sexual relationships with others predicted overall quality of life in a positive way. In upper limb amputees the sexual debut of who had their first sexual experience after the amputation was averagedly 3 years later compared with upper limb amputees who had their debut before amputation [13].

## Discussion

In the last 60 years, only 11 studies (the papers of Walters and Williamson present probably the same study population [8,18]) concerning sexuality and amputations of extremities could be identified. The studies were characterised by a diversity of study populations, sampling methods, gender and age distributions, assessment methods and outcomes measures. This diversity may be related to the large time span over which the studies were performed. Only cautious comparisons can be made between results of the different studies. The outcome measures such as sexual adjustment, sexual functioning or sexual function are not well enough operationally defined and thus we are not sure whether the same construct is measured in the different studies or a closely related construct. In 2001, the International Classification of Functioning, Disability and Health (ICF) was accepted by the World Health Organisation [19]. The aim of the ICF is to provide a unified and standardised language for describing and classifying health domains and health-related states and hence to provide a common

framework for health outcome measurements. Sexual functioning is described in the ICF but should be further elaborated upon (better defined terminology) because the current definitions allow diversity of interpretation. In the ICF sexual function is described as: Mental and physical functions related to the sexual act, including the arousal, preparatory, orgasmic and resolution stages (Inclusions: functions of the sexual arousal, preparatory, orgasmic and resolution phase: functions related to sexual interest, performance, penile erection, clitoral erection, vaginal lubrication, ejaculation, orgasm; impairments such as in impotence, frigidity, vaginismus, premature ejaculation, priapism and delayed ejaculation).

The authors think that using the ICF definitions and using measurement instruments accordingly, outcomes of future research can be more easily compared regarding sexuality and amputation. All studies identified had a cross-sectional study design. Therefore, it is not sure whether the associations between amputation and sexuality are causal. It is possible that loss of libido or erectile problems were already present prior to the amputation due to the underlying disease. After amputation many of the elderly patients are sent to a nursing home or rehabilitation centre for rehabilitation treatment. The younger ones get outpatient treatment. The aim of the rehabilitation treatment is reintegration in society. This goal is aimed for by reducing the ADL related disabilities due to amputation. Additionally there should be focus on the psycho-social functioning such as acceptance and at participation and reintegration in society and returning to work. The level of sexuality, sexual functioning and sexual satisfaction seems to be an under lighted area. The finding that amputation had a higher impact on sexual functioning in elderly compared to younger amputees might also be an age effect unrelated to the amputation. Also adaptation in sexual behaviour or for example obtaining other positions during coitus may be more difficult for elderly.

Another problem is that recall bias may have occurred when the amputees were asked to compare the current state with the state prior to amputation, especially when the time interval between amputation and study was large.

Being married or having a steady partner as an amputee give fewer problems in sexual functioning than being single. This may be due to the fact that it is perhaps more difficult to start a sexual relationship as when visible impaired as an amputee than being amputated in the environment of having a (married) partner.

One conclusion that can be drawn from most publications is that a variable amount of the amputees (13–75%) are not satisfied with their sexual life, despite unchanged interest in sex. In one paper [14]

transfemoral amputees reported significantly more sexual problems than transtibial amputees, however sexual activity was not a serious problem. Male amputees appear to have more sexual problems than female amputees, possibly due to the traditional position of the man namely at top or due to the broken ego of men in which 'sex' is a bigger issue. In a similar literature search regarding sexuality and rheumatic diseases there was no difference between men and women regarding sexual problems [20].

In many papers the authors suggest that there should be more attention and understanding for sexual problems of the amputees. This recommendation has not lead to a pile of studies. A taboo to speak about sexuality may be a reason for the lack for this interest in studies. In the study of Ide et al. [11] none of the respondents talked about sexual issues with the medical professionals.

Assessment of sexual functioning should be an integral component of the periodic evaluation scheme in the rehabilitation team. One or more members of the team should be trained for that assessment.

In scientific research more focus should be on sexuality with the use of one terminology and that should be the ICF. Finally, based on this systematic review, we support Ide et al. [11] who stated that it is surprising that our knowledge of sexual aspects of limb amputees has not widened very much in the last decades.

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